Health Information Seeking Behavior of Individuals with Hearing Loss in an Online Community

Biyang Yu[1], Jongwook Lee[1], Hang Dong[2]
[1]Florida State University
[2]Xi'an Jiaotong-Liverpool University

Abstract
To address the dearth of research on the behavior of individuals with hearing loss who seek health information, this pilot study was designed to explore their health concerns and information needs in an online community, AllDeaf. The authors analyzed 559 health questions asked in the community forum, *Lifestyle, Health, Fitness & Food*. Specifically, the authors coded the types of information and information sources sought by participants, as well as their health concerns. The findings showed that ear problems and mental health issues were the main health concerns of people with hearing loss, and they tended to seek factual information about other members' similar experiences. This study can contribute to our understanding of health information behavior of people with hearing loss, and sheds light on the improvement in, and the development of, health information services that are customized to their information needs.
Keywords: Health information seeking; people with hearing loss; online communities; health information service
doi: 10.9776/16529

Contact: by13b@my.fsu.edu

1 Introduction

Online communities have been used frequently to exchange health information as they are easy to use and provide information that is useful (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Such communities allow people to meet "virtually" and have textual conversations on specific health-related topics, such as cancer and heart disease (Klemm et al., 2003). Although health information sharing is heavily addressed for the general population (Klemm et al., 2003) and some disadvantaged minorities (Kim & Yoon, 2012; Pfeil et al., 2010), relatively few studies have been conducted to address the online health information behavior of people with hearing loss, which includes approximately 7.6 million people in the United States (Brault, 2012), and 15-26% of the world's population (Pollard Jr., Dean, O'Hearn, & Haynes, 2009).

Individuals with hearing loss prefer to acquire or share information through a variety of online communities that are designed for them, because of their relatively low literacy level and cultural preferences (Valentine, Skelton, & Levy, 2006) . Further, their less effective communication and health self-management skills make them more vulnerable to health problems than are individuals without disabilities (Pollard Jr. et al., 2009), suggesting that it is necessary to understand their health information behaviors in order to develop and improve the online services available to them. As a first step in understanding the information behaviors of people with hearing loss, this pilot study was designed to explore their health concerns and information needs in an online community.

2 Research Questions

Three research questions were posed to understand health concerns and information seeking of people with hearing loss in an online community.

RQ 1. What types of health concerns do people with hearing loss express in online communities?
RQ 2. What types of health information do people with hearing loss seek in online communities?
RQ 3. What types of information sources do people with hearing loss seek in online communities?

3 Methods

3.1 Data Collection

To explore the health information seeking behavior of people with hearing loss, the authors selected an online community AllDeaf (http://www.alldeaf.com/), one of the leading online communities for the

population, which includes 62,742 members and 111,379 threads as of September, 2015. The majority of the health-related issues were discussed in the forum, *Lifestyle, Health, Fitness & Food*. For this study, the authors firstly collected 1,835 health-related threads out of 3,720 threads using the keywords related to health (e.g. health, disease). One of the authors determined if health questions were asked in the 1,835 threads by checking the very top post within each thread and found that 559 threads included health-related inquiries, which were the focus of data analysis in this pilot study.

3.2 Coding and Analysis

The authors coded the health concerns of people with hearing loss according to sixteen categories suggested by MedlinePlus (http://www.nlm.nih.gov/medlineplus/healthtopics.html). With respect to the types of information, the authors used three categories identified by Savolainen (2011a): (1) factual information, (2) opinions or evaluations, and (3) procedural knowledge. Based on Savolainen's (2011b) work, factual information was operationalized as information with "free of value judgments", while opinions or evaluations was operationally defined as information about "attitudes, beliefs, and value-based judgments". Procedural knowledge refers to information about solving health related problems. Moreover, the types of information sources were coded based on Savolainen's (2011a) six categories: (1) personal knowledge (own experience); (2) expert or expert organization; (3) human sources; (4) networked sources; (5) printed sources; and (6) other sources. The authors assigned multiple codes (i.e., information types and source types) to each question if applicable. Two authors checked inter-coder reliability using 20% of the questions and achieved 81% of agreement.

4 Findings

4.1 Types of Health Concerns

Fifteen types of health concerns were found in the questions (Table 1). The health issues addressed most frequently were related to *Ear, Nose, and Throat* (16.3%); primarily ears. Inquiries about ears were not restricted to hearing loss, but also concerned tinnitus, ear infections, and ear pain with or without hearing aids. The second set of concerns inquired about most frequently was related to *Mental Health* (13.6%). With respect to the latter, people suffered from anxiety, depression, post-traumatic stress disorder (PTSD), or mood swings. 12.0% of questions were not related directly to health, but addressed other issues, such as hospital service, health insurance, and doctors.

Health Concerns	Numbers of Questions
Ear, Nose, and Throat	91 (16.3%)
Mental Health	76 (13.6%)
Female Reproductive System	47 (8.4%)
Digestive System	36 (6.4%)
Eyes and Vision	28 (5.0%)
Skin, Hair and Nails	22 (3.9%)
Substance Abuses	17 (3.0%)
Lungs and Breathing	13 (2.3%)
Mouth and Teeth	13 (2.3%)
Endocrine System	13 (2.3%)
Immune System	10 (1.8%)
Kidneys and Urinary System	8 (1.4%)
Nutrition	8 (1.4%)
Male Reproductive System	2 (0.4%)
Others	67 (12.0%)
Total	559

Table 1. Distribution of Health Concerns

4.2 Types of Information Asked in Questions

As shown in Table 2, over three quarters of the questions (76.2%) were related to factual information about health concerns. Participants were primarily interested in the experiences of other members who suffered from similar health problems; for example, a recently deafened person with PTSD sought factual information, asking whether other members have experienced PTSD due to hearing loss. In addition, several people were interested in the interpretations of test results, professional sources, and pricing.

Types of Information	Numbers of Questions
Factual Information	426 (76.2%)
Opinions/evaluations	108 (19.3%)
Procedural Information	87 (15.6%)
Unstated	4 (0.7%)
Total	559

Table 2. Distribution of Information Types

Opinions/evaluations and procedural information were addressed less often. Participants sought opinions or evaluations that would help them diagnose their health problems, evaluate certain treatments, or understand the influences of health policies (e.g., new insurance). They also asked for procedural knowledge and were interested in possible treatments or remedies to deal with various health problems. In particular, in some questions, multiple information types were sought in a single question. For example, a person suffering from ADHD asked both factual ("if anyone here had it") and procedural information ("what you do to help yourself with it"). For those questions regarding factual information, 58 (13.6%) threads are also related to procedural information or evaluations. However, only 5 questions asked both opinions and procedural information.

4.3 Types of Information Sources Addressed

The information asked for most frequently was personal knowledge (own experience: see Table 3). Many participants were interested in learning about other members' experiences. Some question types were: "Anyone here experienced…?", "Does anyone have similar problems?", "Has anyone tried…?", or "How do you deal with…?"

Types of Information Source	Numbers of Questions
Personal knowledge	402 (71.9%)
Expert or expert organization	5 (0.9%)
Networked sources	4 (0.7%)
Human sources	3 (0.5%)
Unstated	145 (25.9%)
Total	559

Table 3. Distribution of Information Sources

Quite a few participants mentioned other types of information sources. These users sought information about experts/organizations, networked sources, and human sources. Printed sources were not mentioned in any questions. Notably, approximately one fourth of all participants did not state their preferred type of information sources explicitly, indicating that they were open to all types of information sources.

5 Discussion and Conclusions

The findings of this study showed that ear problems and mental health issues were the main health concerns of people with hearing loss. These findings support prior studies demonstrating that the population that suffers from hearing loss is also likely to have ear infections/tinnitus (Vio & Holme, 2005), as well as mental health problems (Fellinger et al., 2012). Although several prior studies found that diabetes and obesity were among the main health problems of the deaf (Emond et al., 2015), such issues were discussed less often in this online community. Rather, it was found that other health concerns, such as female reproductive systems, digestive systems, and eye/vision, were other main health problems for people with hearing loss.

While Savolainen's (2011a) study suggested that opinions or evaluations were the types of information addressed most often (72.3%), this study found that factual information was sought most frequently (71.2%). This discrepancy may be due to either different information seeking behaviors related to the context of communities and health conditions (people with hearing loss vs. people with depression concern (Savolainen, 2011)) or different coding criteria which requires further examination. With respect to the types of information sources, although Savolainen's (2011a) study focused on answers rather than questions, his findings were similar to those in this study, showing that personal knowledge was the most popular source.

This pilot study suggested that people with hearing loss tended to seek factual information about other members' similar experiences. Seeking information about shared experiences might be related to the cultural preference of people with hearing loss (Ladd, 2003). However, whether or not they needed factual information, or sought opinions/evaluations, should be examined further in a follow-up study, as the questioners might have sought opinions or information about evaluations implicitly, while asking explicitly about factual information. In future studies, the authors will extend their analysis to answers, examine user perceptions of online communities as information worlds, and apply social frameworks to deepen our understanding of the information behaviors of people with hearing loss.

6 References

Brault, M. (2012, July). Americans with disabilities: 2010. Retrieved from http://www.census.gov/prod/2012pubs/p70-131.pdf.

Emond, A., Ridd, M., Sutherland, H., Allsop, L., Alexander, A., & Kyle, J. (2015). The current health of the signing Deaf community in the UK compared with the general population: a cross-sectional study. *BMJ Open, 5*(1), e006668.

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ, 328*(7449), 1166-1171.

Fellinger, J., Holzinger, D., & Pollard, R. (2012). Mental health of deaf people. *The Lancet, 379*(9820), 1037–1044.

Kim, S., & Yoon, J. (2012). The use of an online forum for health information by married Korean women in the United States. *Information Research, 17*(2), 411-436.

Klemm, P., Bunnell, D., Cullen, M., Soneji, R., Gibbons, P., & Holecek, A. (2003). Online cancer support groups: a review of the research literature. *Computers, Informatics, Nursing : CIN, 21*(3), 136–142.

Ladd, P. (2003). Understanding deaf culture: In search of deafhood. Clevedon, England: Multilingual Matters Ltd.

Pfeil, U., Zaphiris, P., & Wilson, S. (2010). The role of message-sequences in the sustainability of an online support community for older people. *Journal of Computer-Mediated Communication, 15*(2), 336–363.

Pollard Jr., R. Q., Dean, R. K., O'Hearn, A., & Haynes, S. L. (2009). Adapting health education material for deaf audiences. *Rehabilitation Psychology, 54*(2), 232–238.

Savolainen, R. (2011a). Requesting and providing information in blogs and Internet discussion forums. Journal of Documentation, 67(5), 863–886.

Savolainen, R. (2011b). Asking and sharing information in the blogosphere: the case of slimming blogs. *Library & Information Science Research, 33*(1), 73–79.

Valentine, G., Skelton, T., & Levy, P. (2006). The role of the Internet in D/deaf people's inclusion in the information society. Retrieved from http://www.geog.leeds.ac.uk/projects/deafweb/FullDeaf%20report.pdf

Vio, M. M., & Holme, R. H. (2005). Hearing loss and tinnitus: 250 million people and a US$10 billion potential market. *Drug Discovery Today*, *10*(19), 1263–1265. http://doi.org/10.1016/S1359-6446(05)03594-4